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## Review article

# Meanings of the sickening process for patients with systemic lupus erythematosus: a review of the literature<sup>☆</sup>



Vera Lucia Pereira Alves<sup>\*</sup>, Andreia Queiroz Carniel, Lilian Tereza Lavras Costallat, Egberto Ribeiro Turato

Universidade Estadual de Campinas (UNICAMP), Campinas, SP, Brazil

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## ABSTRACT

Systemic lupus erythematosus is an autoimmune disease that causes many psychological repercussions that have been studied through qualitative research. These are considered relevant, since they reveal the amplitude experienced by patients. Given this importance, this study aims to map the qualitative production in this theme, derived from studies of experiences of adult patients of both genders and that had used as a tool a semi-structured interview and/or field observations, and had made use of a sampling by a saturation criterion to determine the number of participants in each study. The survey was conducted in Pubmed, Lilacs, Psycinfo e Cochrane databases, searching productions in English and Portuguese idioms published between January 2005 and June 2012. The 19 revised papers that have dealt with patients in the acute phase of the disease showed themes that were categorized into eight topics that contemplated the experienced process at various stages, from the onset of the disease, extending through the knowledge of the diagnosis and the understanding of the manifestations of the disease, drug treatment and general care, evolution and prognosis. The collected papers also point to the difficulty of understanding, of the patients, on what consists the remission phase, revealing also that this is a clinical stage underexplored by psychological studies.

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<sup>☆</sup> Department: Graduation Program in Medical Sciences/Mental Health Area, Universidade Estadual de Campinas, Campinas, SP, Brazil.

<sup>\*</sup> Corresponding author.

E-mail: [vera@alves.com.br](mailto:vera@alves.com.br) (V.L.P. Alves).

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## Significados do adoecer para pacientes com lúpus eritematoso sistêmico: revisão da literatura

### R E S U M O

#### Palavras-chave:

Lúpus eritematoso sistêmico

Doença crônica

Adaptação psicológica

Pesquisa qualitativa

O lúpus eritematoso sistêmico é uma doença autoimune, que provoca diversas repercussões psicológicas que têm sido estudadas por meio de pesquisas qualitativas. Essas são consideradas relevantes, uma vez que reveladoras da amplitude vivenciada pelos pacientes. Face a essa relevância, este artigo buscou mapear a produção qualitativa na temática, oriunda de estudos de vivências de pacientes adultos de ambos os gêneros e que tivessem usado como instrumento a entrevista semiestruturada e/ou a observação de campo, além do critério de amostragem por saturação na definição do número de participantes de cada estudo. O levantamento foi feito nas bases de dados Pubmed, Lilacs, Psycinfo e Cochrane em busca de produções em língua inglesa e portuguesa publicadas entre janeiro de 2005 e junho de 2012. Os 19 artigos revisados que se ocuparam com pacientes em fase aguda da doença revelaram temas categorizados em oito tópicos que contemplaram o processo vivenciado nas diversas etapas, desde o desencadeamento da doença, passando pelo conhecimento do diagnóstico pela e compreensão das manifestações da doença, até o tratamento medicamentoso e os cuidados gerais, a evolução e o prognóstico. Apontam também a difícil compreensão pelos pacientes do que consiste a chamada fase de remissão, bem como nos revela que se trata de uma fase clínica pouco explorada pelos estudos psicológicos.

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## Introduction

Systemic lupus erythematosus (SLE) is a disease with multisystemic, chronic and inflammatory characteristics that affects mostly young women, in a ratio of nine women to one man. Some authors attribute the onset of SLE to hormonal, genetic, environmental and emotional factors.<sup>1,2</sup>

The scientific literature reports that often many patients end up being accompanied by various medical specialties to obtain the correct diagnosis of the disease. Therefore, visits to the doctor and the ever recurring symptoms are referred to as factors that trigger feelings of insecurity, fear, anxiety and stress.<sup>3</sup> With the diagnosis, these sensations, settled or not, will be accompanied by other emotional states, now stemming from the treatment, which can accentuate this condition of personal uncertainty.<sup>3</sup> And these are experiences that qualitative trials aspire to study, in an attempt to understand them dynamically,<sup>4</sup> as well as their interrelationship, to enable coping with the whole treatment process. The goal of these studies is to contribute to more assertive practices toward the SLE patient, assisting in his/her quality of care.

Given the relevance of these experiences and their little exploitation in the scientific literature by means of qualitative methodology, a bibliographic study of the subject was developed, in order to map the findings of this research model targeted to the specific exploration of the meanings attributed by patients with SLE.

Our aim is that the study will contribute to the understanding of the configuration of the emotional aspects that pervade the experience of the treatment of SLE patients already exploited in this literature, and for the indication of those still not studied, in order to facilitate increasingly the approach by health professionals.

## Method

This review was based on a survey conducted in PUBMED, LILACS, PSYCINFO and COCHRANE databases, from January 2005 to June 2012. In our search strategy, we used the descriptor "Lupus" combined with "Qualitative study". The survey resulted in 28 articles and of these, 19 met the inclusion criteria: publications in English and/or Portuguese language whose studies had prioritized the experiences of adult patients of both genders with SLE; and, with that in mind, that had used semistructured interviews and/or field observations as tools; and that also have made use of the sampling criterion by saturation to determine the number of participants.

The 19 articles were read in full and their findings were analyzed, synthesized in an integrative way and grouped into thematic categories.<sup>5</sup> The preparation of these categories was validated by investigators of the research group of the authors.

## Results

With this bibliographic search, it was possible to confirm the growing interest, especially in the last seven years, for qualitative studies on the sickening process in patients with SLE. This is an editorial phenomenon, which is more frequent from 2006 onwards. Prior to this period, in addition to being scarce, qualitative studies were devoted only to describe data on disease symptoms, superposing with results from studies of quantitative nature.

The production analyzed, illustrated in [Table 1](#), had different origins.<sup>6-24</sup> Nine articles showed results of studies conducted in Europe; four in Latin America; five in North America and one in Asia. However, no study on experiences of

**Table 1 – Studies reviewed.**

Author, country (year)	Number of patients in each study	Results	Main outcome
Gallop K, Nixon A, Swinburn P, Sterling KL, Naegeli AN, Silk ME. USA (2012) <sup>24</sup>	22	The study illustrates the great impact that the symptoms cause in the patient's life and the potential of treatment in improving symptoms of the disease.	Symptoms of the disease represent a large part in patients' lives, which hinders their day-to-day routine.
Mattson M, Möller B, Stamm T, Gard G, Boström C. Sweden (2011) <sup>21</sup>	19	It was found that SLE patients live among uncertainties and the new opportunities provided by the disease.	In general, patients perceive the future as something uncertain, reporting that their therapeutic contact with professionals helps in the treatment.
Waldon N, Brown S, Hewlett S, Elliott B, McHugh N, McCabe C. UK (2011) <sup>20</sup>	43	It was found that patients requested better clarification in the post-diagnosis, in addition to professional help.	In general, participants stated that the support provided at the time of the diagnostic information was insufficient for their needs. They would like to obtain more detailed information, by various means, provided that basically backed up by professionals and available at any time of the patient's trajectory. The challenge for health professionals is to meet those needs in the most beneficial and effective way.
Kumar K, Gordon C, Barry R, Shaw K, Horne R, Raza K. UK (2011) <sup>19</sup>	32	There was a request for further information about drugs, longitudinal effects on the medication and the individuality of each patient.	The influence of spiritual beliefs, concerns about side effects of medications, religious beliefs about the incidence of disease and barriers to communication with professionals regarding medication were found. In general, a negative way to understand the importance of the medication can be perceived, which reveals a need for educational intervention for medication adherence.
Berckerman NL. USA (2011) <sup>16</sup>	32	Relevant topics presented by patients: depression, uncertainties about the disease, emotional fatigue and physical and financial hardships.	Emerging themes indicated high vulnerability to depressive states. Manifestations of depression and anxiety are related to the management of the uncertainty of the disease and to physical and emotional stress arising from the experience of a chronic disease, as well as to the associated financial aspects. Such psychosocial aspects must be considered, from the screening to the evaluation and planning of psychosocial treatment with this population.
McElbhone K, Abbott J, Gray J, Williams A, Teh LS. UK (2010) <sup>15</sup>	30	Relevant themes were: prognosis and course of the disease, body image, effects of treatment, fatigue/pain, losses, specific care, cognition and pregnancy	It has been found through research that the majority of respondents perceive a negative impact of SLE on their lives. The results presented in this study identified important issues that can inform physicians about SLE patients' outlook, enabling these professionals to undertake a new management with respect to symptoms presented during the course of the disease
Pettersson S, Möller S, Svenungsson E, Gunnarsson I, Welin Henriksson E. Sweden (2010) <sup>22</sup>	33	The report of the patients suggests that they can control fatigue in their lives in various situations, but in most cases, its occurrence severely limits the daily life routine.	Health professionals are encouraged to take a more active role to empower people with SLE to meet their own balance, as a way to achieve a situation of "being in control".
Woods-Giscombe C L. USA (2010) <sup>18</sup>	48	Interests in the role of patients for family/community preservation, as well as interests of self-preservation.	The results of this study indicate that the role of "Wonder Woman" is a multidimensional phenomenon that encompasses features such as the obligation to express strength, emotional suppression, demonstrate resistance to vulnerability and dependency, determination to succeed and obligation to help others. According to the women in this study, the role of "Wonder Woman" involves socio-historical and personal contextual factors as well as themes of survival and health status.
Robinson D, Aguilar D, Schoenwetter M, Dubois R, Russak S, Ramsey-Goldman R et al. USA (2010) <sup>17</sup>	23	Patients reported their clinical doubts with respect to pain, fatigue, withdrawal from work/school and skin problems	In general, SLE patients report symptoms that could significantly affect their daily life functioning. Treatments that substantially improve disease manifestations will offer considerable benefits for patients, medical treatment and society.

**Table 1 – (Continued)**

Author, country (year)	Number of patients in each study	Results	Main outcome
Wittmann L, Sensky T, Meder L, Michel B, Stoll T, Büchi S. Switzerland (2009) <sup>11</sup>	12	Various forms of suffering alleviated with personal reorganization when facing disease.	The results were consistent with the concept of suffering as a psychological process triggered and sustained by a threat of assessment, to the self or “personality”. The results suggest that the various types of pain have to be differentiated. Thus, recognizing personal growth, in response to the experience of illness, is something that can reduce suffering.
Chambers SA, Raine R, Rahman A, Isenberg D. UK (2009) <sup>13</sup>	220	The main reason suggested is the prolonged use of medications, and their side effects.	The reasons for patients to take (or not take) their drugs are largely related to previous experiences with the disease. However, an improvement in communication between doctors and patients may promote better adherence in SLE patients.
Chambers S, Rine R, Rahman A, Hagley K, De Ceulaer K, Isenberg D. UK (2008) <sup>14</sup>		Noncompliance presented, as factors: cost and difficulty of obtaining the medication, in addition to side effects.	Conclusion: Socio-economic constraints and limited availability of drugs are particularly important influences on the low adherence in Jamaican SLE patients. Religious beliefs and the use of herbal remedies do not seem to adversely affect adherence, but are used when the medication can not be obtained.
Stamm TA, Bauernfeind B, Coenen M, Feierl E, Mathis M, Stucki G, et al. (2007) <sup>9</sup>	21	Overall, one can verify similarities between the evaluation instruments and concepts stemmed from patients: body, emotional factors, environmental factors and personal factors.	Disease activity affects personal, social and interactional factors.
Araújo AD, Traverso-Yepey M. Brazil (2007) <sup>23</sup>	8	Various forms of significance were found in the patients, changing with the progression of the disease.	One needs an interdisciplinary approach to disease complexity, considering the biopsychosocial dimension involved in the process, given the many meanings attributed by respondents.
Costernbaden KH, Brome D, Blanch D, Gall V, Karlson E, Liang MH. USA (2007) <sup>10</sup>	40	Demographic factors were important in decisions on prevention: study, personal benefit, physical impairment.	The purpose in determining what are the factors considered by patients with SLE, while participating in trials of disease prevention, as well as if the disease correlates with the study design, was answered concluding that similar factors have different weights between participants and nonparticipants. Thus, the results suggest that processes of health education, physician recruitment and limiting the time required, may increase the recruitment of patients with SLE for clinical prevention trials.
Meldson C. USA (2006) <sup>12</sup>	30	The main factor reported by patients was the cognitive impairment after diagnosis.	The complexity of a life with lupus is multidimensional, with regards to overlapping issues. Life with lupus is identified as an life of uncertainty, with a sense of identity change and the need to deal with the financial burden arising from the disease.
Mattje GD, Turato ER. Brazil (2006) <sup>8</sup>	5	Change in life routine for patients and the concepts they construct about their illness were observed.	The reactions of the patients included an attempt to rebuild their relationships relying on their own strengths. Family and interpersonal conflicts of these patients appear to be associated with the idea that family and friends do not understand the nature of the disease.
Hale ED, Trehame GJ, et al. Reino Unido (2006) <sup>6</sup>	10	Patients do not understand the precautions to be taken. Further information from professionals on the subject are suggested.	SLE patients do not feel that are understood by health professionals or by the people close to them. The support of trained volunteers and patients with SLE can ensure a better information, because these are individuals with personal experience. These services can improve communication and help minimize the isolation of patients with SLE.
Goodmamn D, Morrissey S, Graham D, Bossingham D. Australia (2005) <sup>7</sup>	36	The results point to different forms of perception of the disease, which are modified with the sickening process.	Professionals should be prepared for the likelihood of changes in the representations of the disease throughout its evolution, as this can be useful in interventions in patients with SLE.

sexuality, spirituality or even on interpersonal relationships of patients with SLE, nor on the experiences of caregivers of SLE patients were found. Also, no studies targeted to the experiences of health professionals dedicated to these people were published.

It is worth noting that the articles did not reveal how long the SLE patients had the disease at the time of the interviews, nor provided data to clarify whether these patients were in stages of recurrence of the disease.

The studies analyzed allowed an integrative synthesis of what has been understood in relation to the different experiences of participants in the study of SLE patients, as observed in studies that have examined the experiences of these patients during the acute and active phase of the disease. These findings are those that were grouped into eight thematic categories, and which are described in this article.<sup>5</sup>

### *The difficulty in obtaining a diagnosis*

In the 12 articles analyzed, the difficulty shown by patients in dealing with waiting until completion of the diagnosis was evident – an event hitherto regarded as a generator of anxiety and uncertainty. Thus, this situation is considered as a factor that triggers emotional problems, such as depressive reactions. Similarly, we found in these articles the idea of a reassuring effect at the time of presentation of the nosological diagnosis.<sup>6-12,17,19,20,22,24</sup>

### *An understanding of the disease*

The authors of six of the studies outlined how, after obtaining the diagnosis, some patients could not understand the constitution of the disease, even after receiving medical advice. This experience was understood as the result of a resistance to the diagnosis, because the act of to deny it or not to understand the chronicity of the disease resulted sometimes in not accepting the need for a longitudinal treatment. This behavior was considered as being connected with nonadherence to treatment.<sup>7,11,12,14,19,20</sup>

### *An understanding of the disease by third-parties*

On the other hand, six other studies revealed the difficulty of caregivers of SLE patients in understanding the disease. These difficulties were related mainly to the peculiarities of the disease, for instance, the phases of exacerbation or remission.<sup>6,8,11,12,14,17</sup>

### *Temporal change of the body*

Authors of 12 studies indicated the body transformation experienced by some patients as something painful, both in the physical and emotional sense. The body transformation was identified as stemming from the clinical symptoms (pain, swelling, and alopecia), as well as from the treatment itself, when, for example, the use of some medications cause fluid retention.<sup>6-14,17,21,24</sup>

### *The experience of fatigue*

The respondents, as suggested in thirteen of the studies, described fatigue as a recurring thing, which persisted even with the disease under control. The results of these articles outlined negatively the fatigue experienced, by hindering routine activities, both current and old.<sup>6-12,15-17,20-24</sup>

### *Return to daily routine*

The yearning for the return of the old life routine and for the realization of future plans was another experience pointed in eight studies. In certain cases, as described by their authors, there was the expectation, on the part of the patient, that the disease would die out over time, thus allowing that these people could conclude their interrupted life projects.<sup>6-8,10,12,22-24</sup>

### *Indefinite use of medications*

Eight studies were dedicated specifically to questions about medications. However, in the analyzed texts the experience of using the medication was described by patients as a negative event in their lives, given the continued and indefinite use or the side effects of drugs. The use of medication was quoted as meaning a condition of “being still sick”, even when the patient had no symptoms of the old acute period of the disease.<sup>6,7,10,12-14,20,22</sup>

### *Access to the professional support needed*

The professional support was appointed by authors of five studies as another difficulty experienced by patients. Sometimes, such support was referred to as difficult to access, especially to answer questions about the disease itself. At other times, this support was referred to as deficient in understanding the uniqueness of each patient.<sup>6,7,13,20,21</sup>

The reviewed studies showed the uniqueness of the different experiences of SLE patients. Together, these studies show a configuration for different experiential stages of the disease, beginning with its emergence, extending to the diagnosis and prognosis, through the understanding of the process of “being sick” and by drug treatment and their evolutionary effects on the disease. The studies also allow us to verify that patients with SLE live in the natural expectation of improvement in their symptoms; however, when remission occurs, there are difficulties in understanding the persistence of the chronic nature of the disease. This moment can be seen as a cure for some patients, whereas in truth, is actually just one stage of the disease that deserves to be better exploited (an aspect not addressed by studies) and that the amplitude of qualitative methods – as this study has shown – helps to outline, facilitating the understanding of the experiences of these patients – in fact at all stages – as well as their handling by the patient.

### **Conflicts of interest**

The authors declare no conflicts of interest.



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